

# Symptom recognition in advanced cancer. A comparison of nursing records against patient self-rating

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The aim of the study was to investigate the extent to which the symptoms experienced by advanced cancer patients were covered by the nursing records. On the day of the first contact with our palliative care department, a nursing record was taken, and on this or the following day, 56 patients filled in the questionnaires EORTC Quality of Life Questionnaire (EORTC QLQ-C30), Edmonton Symptom Assessment System (ESAS), and Hospital Anxiety and Depression Scale (HADS). In each patient, the symptomatology reported in the patient-completed questionnaires was compared with the symptomatology mentioned by the nurse in the nursing record. The analysis revealed good concordance concerning pain and poor physical functioning, but

patients reported other symptoms or problems much more often than their nurses. Reasons for these discrepancies are discussed. It is suggested that the nurse's knowledge of the patient's symptomatology might gain from more systematic screening or from transfer of information from patient self-assessment questionnaires to the nursing records.

**Key words:** Palliative care; advanced cancer; symptomatology; self-assessment questionnaire; quality of life; nurse.

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PALLIATIVE CARE aims at alleviating as many of the patient's symptoms as possible, thus providing "the best quality of life for patients and their families" (1). In order to achieve this goal, the medical staff must have precise knowledge of the patient's condition and needs, and the nursing record serves as an important instrument in the treatment and care of the patient. Ideally, the record contains every symptom and problem the patient might have: if a symptom is not mentioned, it is unlikely that it will be treated. However, there is reason to suspect that professionals do not always detect all aspects of the patient's symptomatology. In a literature review, Sprangers and Aaronson (2) found low to moderate levels of concordance between symptoms assessed by the patient versus symptoms assessed by physician or nurse.

In our department of palliative medicine, a four-year prospective research project is being conducted, including all patients referred to the department. The project aims to evaluate the effect of palliative care and to develop and validate methods for this. The patients fill in questionnaires assessing their physical and psychological symptomatology.

In a previous paper (3), we investigated the extent to which the doctors recognised the symptomatology reported in questionnaires by palliative care patients. We found good concordance concerning pain, but

many other symptoms experienced by patients seem to be undetected by their doctors. In this paper, we examine if this is also the case for the nursing staff.

If it is true that palliative care nurses do not fully know their patients' symptomatology, one could argue that the information contained in patient-completed questionnaires should be made available to nurses. The usefulness of this has previously been suggested (4–6) but has not been formally evaluated in palliative care. The present study elucidated aspects of this question. The aim of the study was to examine the extent to which the initial symptomatology reported by patients in self-assessment questionnaires was covered by the nursing records.

## Methods

### Patients

From June 3<sup>rd</sup>, 1998, to May 26<sup>th</sup>, 1999, 102 patients were admitted to the Department of Palliative Medicine at Bispebjerg Hospital, Copenhagen. Patients admitted to the department must have advanced cancer for which no curative or life-prolonging treatment can be offered, and have pronounced palliative needs. Inclusion criteria for the above-mentioned prospective study were referral to the department, Danish speaking, age  $\geq 18$  years, and informed consent. The local

Ethics Committee approved the study. In the present paper, we use the data from the 56 eligible patients consenting to participate in the study. Of the 102 patients, one patient was less than 18 years old and three patients were excluded due to insufficient knowledge of the Danish language. Two patients started out as outpatients and did not have a nursing record taken from the day of first contact with the department. The remaining 40 patients declined participation or were not asked due to poor health status.

### Measures

*Patient self-assessment:* On the day of first contact with the department or the next day, the patients were given a questionnaire booklet including the Edmonton Symptom Assessment System (ESAS) (6), the European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Questionnaire (QLQ-C30) (7), and the Hospital Anxiety and Depression Scale (HADS) (8). The ESAS and the EORTC QLQ-C30 are designed to cover several aspects of the patient's health-related quality of life (physical as well as psychosocial aspects). The 30-item EORTC QLQ-C30 deals with health and well-being during the previous week. Its items are transformed into six functional scales and three symptom scales, as well as six single items comprising more specific symptoms (9). The ESAS consists of nine visual analogue scales (VAS) where the patient marks the degree to which he is experiencing pain, inactivity, nausea, etc. The 14-item HADS measures anxiety and depression. Respondents can score 0–21 points on each of the subscales on anxiety and depression. According to Zigmond and Snaith (8), 0–7 points on a subscale represents a "non-case", 8–10 points a "doubtful" or possible case, and 11–21 points a "definite case" of anxiety or depression.

The patients could choose whether they wished to complete all of the questionnaires or a subset of items only, in order to make it possible for patients to participate even if they were only able or willing to fill in relatively few items.

*Nursing records:* On the day of first contact with the department, a nursing record was taken, focusing on the patient's palliative needs. Nursing records were available for 56 patients.

*Extraction of data from nursing records:* From the patient-assessed questionnaires, we constructed a checklist containing the nine scales and six single items of the EORTC QLQ-C30, the nine items of the ESAS, as well as anxiety and depression from the HADS. This checklist was used to review the qualitative content of the nursing records: For each

symptom in the checklist it was noted whether or not this symptom was mentioned in the nursing records of each patient.

### Analysis

*Categorisation:* We wished to estimate "nurse's symptom recognition percentage" (NSR), i.e. *the extent to which symptoms experienced by patients are recognised by their nurses*. This requires a definition of which patient responses represent "symptoms". Once this is defined, the NSR is the number of patients having the symptom mentioned in their nursing record, as a percentage of the number of these patients scoring above the threshold in the questionnaires.

Patient responses on the three standard questionnaires were scored according to standard procedures for these instruments (6–9). The only instrument having a definition of "caseness" is the HADS.

It would not make much sense to assume that a patient rating pain as '2' on a 0–100 scale, where 100 corresponds to maximal pain, had any important pain. Furthermore, it was of interest to compare the NSR of patients reporting modest symptom intensity against those reporting severe symptoms. We therefore had to define (arbitrary) thresholds for "having a symptom" based on scores on the ESAS and the EORTC QLQ-C30, i.e. define the lower limit for "having a symptom", and to define thresholds between low, moderate, and high levels of symptoms.

The ESAS scores are in principle continuous on a scale of 0–100 mm, and according to the scoring of manual (8), the responses on the EORTC QLQ-C30 are also converted to a 0–100 scale. For EORTC QLQ-C30 single items, "0" corresponds to "not a problem", "1" to "a little", "2" to "quite a bit", and "3" to "very much". In contrast, there is no simple verbal interpretation of the EORTC QLQ-C30 multi-item scales estimated as the average of 2–5 items or of the ESAS visual analogue scales, both of which have multiple score levels between 0 and 100.

The thresholds we have chosen in order to define the lower limit for "having a symptom", and to define thresholds between low, moderate, and high levels of symptoms were inspired by the values assigned to the response categories of the EORTC QLQ-C30 single items (see above) (Fig. 1). The lower limit for having a symptom was defined as 17. Thus, EORTC QLQ-C30 and ESAS scores 0–16.9 mm were termed "not a problem", 17–33.9 mm "a little", 34–66.9 mm "quite a bit", and 67–100 mm "very much". For dichotomous analyses where we wanted to distinguish patients having a symptom from those not having it, we decided that those scoring 34–100 had a "significant symptom".

“Not a problem” 0–16.9	“A little” 17–33.9	“Quite a bit” 34–66.9	“Very much” 67–100
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0	33.3	66.7	100
Not a problem	A little	Quite a bit	Very much

Fig. 1. Categories used in the present study for scorings on the EORTC QLQ-C30 and the ESAS (above) versus values assigned to response categories in the EORTC QLQ-C30 (below).

These limits were chosen in order to make clinical sense for single items as well as for scales estimated from two or more items. In the latter case we decided, for example, that the score on a scale composed of two items, where one item was scored “a little” and one was scored “quite a bit”, should be categorised “quite a bit”. This procedure attaches interpretations to the ESAS scores which may be disputed but seem reasonable for the use in the present study.

For this analysis, the six functional (positively phrased) scales of the EORTC QLQ-C30 were reversed so that, corresponding to the symptom scales, a high score indicated a poor performance or an unpleasant sensation.

The HADS scores were analysed using the three categories described above (8).

*Cross-tabulation:* The patient’s scores on the ESAS, the EORTC QLQ-C30, and the HADS (categorised as described above) were cross-tabulated against the dichotomous data on whether or not each symptom was mentioned in the nursing records of the same patient.

## Results

The age, sex, and primary site of malignancy of the 56 patients are shown in Table 1. The EORTC QLQ-C30 was completed by 55, the ESAS by 53, and the HADS by 49 of the patients.

According to the EORTC QLQ-C30, patients reported their physical function to be significantly impaired (reversed score  $\geq 34$ ) in 88%, role function impaired in 91%, emotional function in 58%, cognitive function in 49%, social function in 63%, and general quality of life in 86% of cases. “Significant” pain (score  $\geq 34$ ) was recorded by 91%, fatigue by 96%, nausea/vomiting by 44%, dyspnoea by 91%, sleep disturbances by 42%, reduced appetite by 73%, constipation by 43%, diarrhoea by 23%, and financial difficulties by 25% of the patients (data not shown in tabular form).

According to the ESAS, “significant” pain (score  $\geq 34$ ) was experienced by 80%, inactivity by 91%, nausea/vomiting by 47%, depression by 47%, anxiety by 47%, drowsiness by 76%, reduced appetite by 78%, impaired well-being by 85%, and dyspnoea by 55% of the patients.

According to the HADS, “doubtful” and “definite” anxiety was present in 24% and 31% of the patients, and depression in 27% and 41%, respectively.

For the scales or single items of the three questionnaires (down), Table 2 shows the number of patients scoring above the different thresholds, the number of times the symptom was mentioned in the nursing records, and the NSR. The rightmost set of columns shows the figures for patients scoring 34 or above, so-called “significant” symptoms. The four middle sections show the results broken down by patient scores ranging from “not a problem” ( $\leq 16.9$ ) to “a lot” ( $\geq 67$ ).

The highest levels of NSR were seen for pain and poor physical functioning. In most cases where the patient had scored pain  $\geq 34$ , pain was mentioned in the nursing record (NSR 84% and 88% in the EORTC QLQ-C30 and the ESAS, respectively). The nurses recognised poor physical functioning (EORTC QLQ-C30) in 84% of significant cases. In contrast, the NSR was much lower for other symptoms, e.g. for significant nausea/vomiting it was 64% and 58%, for reduced appetite 41%, for dyspnoea 46% and 41%, for fatigue 36%, and for financial difficulties, sleeplessness, low quality of life, and impaired well-being 0%.

Table 1

Demographic data and primary malignancies in 56 patients with advanced cancer.

<i>Demographic data (n=56)</i>	
Sex (F/M): 34/22	
Age (years): mean 61.8 range 39–91	
<i>Primary malignancy</i>	
Lung	14
Breast	8
Colorectal	5
Pancreas	1
Other gastrointestinal	1
Gynaecologic	3
Prostate	7
Other urogenital	6
Sarcoma	4
Head & neck	3
Melanoma	1
Lymphoma	1
Other/unknown	2

Table 2

Nurse's symptom recognition (NSR). The section on the right shows the number of patients having a score of at least 34 on the symptom/problem (Np), the number of these patients for whom it was mentioned in the nursing records (Nn), and the NSR (Nn/Np\*100%). In the middle sections of the table, these figures are shown separately according to patient score.

Patient score	Not a problem/0–16.9				A little/17–33.9			Quite a bit/34–66.9			Very much/67–100			Significant/34–100		
	N	Np	Nn	NSR	Np	Nn	NSR	Np	Nn	NSR	Np	Nn	NSR	Np	Nn	NSR
<i>EORTC QLQ-C30</i>																
Physical function	55	0	0	0	6	3	50	20	12	60	29	29	100	49	41	84
Role function	52	1	0	0	4	0	0	7	0	0	41	5	12	49	6	12
Emotional function	53	3	0	0	19	5	26	18	4	22	13	6	46	31	10	32
Cognitive function	53	1	0	0	16	2	13	22	0	0	14	3	21	36	3	19
Social function	50	8	0	0	12	1	8	15	1	7	15	1	7	30	2	7
Quality of life	51	2	0	0	5	0	0	22	0	5	22	0	0	44	0	0
Fatigue	55	0	0	0	2	0	0	17	4	24	36	15	42	53	19	36
Nausea/vomiting	55	11	1	9	19	6	32	19	11	58	6	5	83	25	16	64
Pain	55	2	1	50	3	2	67	14	9	64	36	33	92	50	42	84
Dyspnoea	54	20	0	0	10	1	10	9	2	22	15	9	60	24	11	46
Sleeplessness	55	23	0	0	6	0	0	16	0	0	10	0	0	26	0	0
Appetite reduction	54	6	1	17	9	2	22	16	5	31	23	11	48	39	16	41
Constipation	54	20	2	15	12	4	33	14	6	43	8	5	63	22	11	50
Diarrhoea	54	27	0	0	14	1	7	3	0	0	10	4	40	13	4	31
Financial difficulties	50	30	0	0	8	0	0	8	0	0	4	0	0	12	0	0
<i>ESAS</i>																
Pain	53	5	3	60	6	4	67	21	18	86	21	19	90	42	37	88
Inactivity	53	1	0	0	4	0	0	8	0	0	40	4	10	48	4	8
Nausea/vomiting	53	22	6	27	5	2	40	16	11	69	10	4	40	26	15	58
Depression	53	20	1	5	7	2	29	14	3	21	12	4	33	26	7	27
Anxiety	53	18	1	6	9	0	0	15	3	20	11	2	18	26	5	19
Drowsiness	53	6	0	0	7	0	0	14	1	7	26	4	15	42	5	19
Reduced appetite	53	7	1	14	5	1	20	7	2	28	34	15	44	41	17	41
Impaired well-being	53	3	0	0	4	0	0	15	0	0	31	0	0	46	0	0
Dyspnoea	51	19	0	0	3	0	0	11	2	18	19	10	53	29	12	41
<i>HADS</i>																
Anxiety	49	22	1	5				<i>Doubtful</i>			<i>Case</i>			<i>Total</i>		
Depression	49	16	4	25				12 1 8			15 4 27			27 5 19		
								13 2 17			20 4 20			33 6 18		

**Abbreviations:** EORTC QLQ-C30=EORTC Quality of Life Questionnaire, ESAS=Edmonton Symptom Assessment System, HADS=Hospital Anxiety and Depression Scale. N=number of patients completing the item, Np=number of cases recorded by patient, Nn=number recorded by nurse, NSR=Nurse Symptom Recognition: percentage of patient-experienced symptoms also noted by nurse.

## Discussion

According to the patient-completed questionnaires, patients experience many symptoms that do not appear in the nursing records (Table 2). The exceptions were pain and poor physical functioning, both of which seem to be noted by the nurse almost every time the patient noted it.

Physical symptoms seem to have a slightly better chance of being detected by the nurse than psychosocial "symptoms" (Table 2, column on the right). Nausea and vomiting was noted in more than half of the cases, and constipation in 50% of cases. The other symptoms and problems were noted by the nurse less frequently, in some cases never (Table 2).

As expected, the nurses more frequently detected symptoms scored high by the patient than symptoms reported as being less severe (compare columns in the

middle of Table 2). For example, in the EORTC QLQ-C30 nausea/vomiting scale, the NSR when the patient scored "not a problem" was 9%, for "a little" 32%, for "quite a bit" 58%, and for "very much" 83%.

As explained in the Methods section, the thresholds we had to define in order to categorise patients' scores on the ESAS and EORTC QLQ-C30 were arbitrary: should the threshold between categories termed "a little" and "quite a bit" be 34 or something different? The important thing to note here is that these thresholds had little impact on the overall results of this study. In fact, the main use of thresholds was to make sure that the estimation of NSR was based on patients reporting at least some symptom intensity: otherwise we would "demand" that symptoms were detected by the nurse even if the patient almost did not report the symptom (e.g. a score of 2 on a 0–100 scale). The use of categories in Table 2 (middle sections) illustrate

that the probability of detection of a symptom increases by its severity. For most interpretations of the data, it is sufficient to inspect the three right hand columns of Table 2 which present the NSR for patients scoring 34 or above on the 0–100 scale.

Patient-reported “significant” nausea/vomiting (scores  $\geq 34$ ) was recognised by the nurse in 64% and 58% of cases (depending on the questionnaire). Significant psychological (e.g. depression, anxiety, cognitive impairment) and more diffuse physical problems (e.g. fatigue and impaired well-being), however, were reported far more often by the patients than by the nurses. Ng and von Gunten (10) found that physicians reported pain and cognitive impairment more often and weakness, fatigue, anxiety etc. more rarely than their patients. In our study, however, nurses also reported cognitive problems less frequently than patients.

In our previous comparison of the medical (doctor’s) record against the patients’ scoring in questionnaires, the doctor symptom recognition rate (DSR), the results were very alike with a high DSR for pain and low values for most other symptoms. The main difference between that and the present study is that the NSR for poor physical functioning is much higher than the DSR. The explanation for this might be that nurses are much more involved in the practical assistance of disabled patients.

When interpreting these results it should be noted that even though consecutive patients were asked to participate, the results apply only to those patients who participated in the study by completing questionnaires. Non-participants were generally those with most advanced disease or impaired cognitive function. It seems likely that the discrepancy between patients and nurses may be even larger for those patients. Therefore, we believe that the bias resulting from non-participation tends to minimise, rather than exaggerate, disagreement between patients and nurses.

Do the findings of low NSRs indicate that nurses have insufficient insight into their patients’ situation – or can they be caused by problems in our methodology?

1. The nursing record is meant to sum up the patient’s most important problems. Therefore, the “deficiencies” in the nursing records should not just be interpreted as inadequacy. First, it is impossible for the nurse to be as detailed as the questionnaires, and she might judge some symptoms or findings too obvious or clinically irrelevant to mention. Second, the nursing record tends to be problem- or action-orientated, emphasising prob-

lems or symptoms for which it is important or simple to take immediate action. As Leder (11) puts it, “the doctor looks not only for disease *per se* but especially for *treatable* diseases”. This may apply to nurses as well.

2. The nursing record was written on day 0, whereas the patient questionnaires were filled in on day 0 or 1. If the patient waited until day 1, he might have collected his thoughts and revealed hitherto unmentioned needs in the questionnaires. Symptoms not mentioned in the initial nursing record might very well surface in the following days. Looking at the magnitude of discrepancy between patient questionnaires and nursing records, it seems unlikely that this mechanism is a major explanation of discrepancy. However, if the nursing records of the following days were also analysed, the NSRs would probably increase.
3. The patient may withhold information or answer incorrectly (in the questionnaires or in the interview for the nursing record), and this will be wrongly interpreted as an error made by the nurse.

In all, however, we do not find that these mechanisms are sufficient to explain the often large discrepancies between patients’ recording of symptoms and their recognition by the nurse. The disagreement found here is larger than found in most studies of patient–doctor agreement (2). However, the results cannot be directly compared, as our comparison of patient-assessment with nursing records must be expected to produce a higher discrepancy: comparing patient self-assessment with nursing records is quite a rigorous way of evaluating the nurse’s ability to detect palliative needs of the patient. If, like in Cull et al. (12), patient self-assessment on psychological distress is compared with assessment performed by the doctor, there is a bigger chance that distress will be revealed, because the doctor is asked specifically if he thinks that the patient is suffering from psychological problems. Slevin et al. (13) compared quality of life measurements (HADS among others) performed by patients and their doctors, and they, too, found low correlations. Brunelli et al. (14) compared patient scorings in the Therapy Impact Questionnaire with scorings of the physician or nurse, and found higher agreement for physical than for psychological or cognitive problems. To our knowledge, the present study is the first to directly compare patient self-assessed symptomatology with the contents of the nursing record.

If patients are systematically interviewed for example about depression, there is a better chance of revealing a “case” than if the patient has to spon-

taneously disclose his mood disturbance. However, questioning in search of a depression will take place only if the nurse suspects the patient of suffering from depression.

The most interesting of the present results concern the palliative needs which might be successfully treated but which – according to the comparison of patient report against nursing record – are often overlooked: Fatigue, nausea/vomiting, dyspnoea, poor appetite, constipation and diarrhoea, as well as anxiety and depression, are all palliative needs for which there is a potential treatment, but they are recognised by the nurse in 20–64% of cases only. Sleeplessness was not noted by the nurses at all.

The present study is in line with the results of other studies suggesting that more systematic screening for symptoms in the initial interview – or systematic use of data from questionnaires filled in by patients – may benefit the patients. For example, Detmar and Aaronson carried out a study in which cancer patients filled in EORTC QLQ-C30 before their outpatient appointment (5). A summary of the scores on the questionnaire was available for the doctor at the consultation. The availability of the summary did not lengthen the duration of the consultation, and it seemed that the QL assessments stimulated the physicians to inquire more into specific aspects of the patient's health and well-being. Schuit et al. (15) suggested that better symptom recognition might be achieved if symptoms were actively assessed.

The participation in research of patients with limited lifetime expectancy is controversial, one of the reasons being that frequent completion of questionnaires may burden the patients. However, information from patient self-assessment questionnaires might be a valuable supplement to nursing records, thus enhancing the probability that the patient's palliative needs are fully recognised by the staff. If this is the case, the efforts made by the patients completing the questionnaires may translate into improved care for the individual patient.

In summary, we have found low concordance between symptomatology as assessed by the patients and the appearance of the same symptoms in the nursing records of patients with advanced cancer. We discuss ways to improve the nurse's detection of symptoms.

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